

Status Report

THE NEWSLETTER OF THE PREMIER'S COUNCIL ON THE STATUS OF PERSONS WITH DISABILITIES

AUGUST 1996

Community Development

Calgary Organizations Join Forces

Non-profit organizations of and for people with disabilities are struggling to remain abreast of funding cut-backs and increasing competition for fundraising dollars. How do such organizations avoid falling by the wayside and remain viable and productive? One answer might be through collaboration: seeking out complementary organizations to share costs and present a united front.

An example of such an alliance is well underway in Calgary. More than two years ago, three distinct organizations—the Accessible Housing Society, the Canadian Paraplegic Association (CPA), and the Technical Resource Centre (TRC)—recognized each other's complementary roles and began discussing the possibility for some form of collaboration. In May, they officially formed a strategic alliance that will be completed in two phases.

The first phase is the formation of a community resource library. With identical grants of \$31,000 from the Muttart and Calgary Foundations, the organizations have hired a coordinator who will begin linking



Nickel, Arndt and Porteus: "A real commitment to work together."

each of its libraries electronically. Staff and clients of each organization will soon be able to access all three libraries—in essence, tripling their former resources.

"Being able to have it on-line means lowering potential for duplication, so that our library dollars will actually go further," says Jan Porteus, Executive Director of the Technical Resource Centre, a non-profit organization that focuses on enhancing independence for people with physical disabilities through the use of advanced technology. "There are bits and pieces that Accessible Housing would purchase and have in its library which we wouldn't have, and the same goes for what CPA has. I think, all around, it's better to have a large collection that none of us are able to afford singularly."

The second phase of the alliance involves moving into common office space. The organizations have juggled their existing leases so that each will expire early in 1997. Each organization expects a host of benefits as a result of the move, including increased awareness of each other's roles, identification of duplication of services, and lowering of costs.

But the greatest impact will be felt by clients, according to Randy Arndt, Supervisor of Rehabilitation Services for CPA, which offers a host of adjustment and vocational counselling services to people with spinal cord injuries. "The goal," says Arndt, "is to try to make it easier for our clients, so that if they're receiving services from us, they don't have to run all the way over to

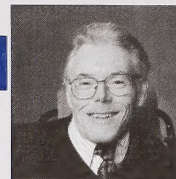
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Bio-ethics: watch your language!

Gary McPherson, LL.D. (Hon.)



Recently, I attended a conference on bio-ethics in Red Deer sponsored by the Provincial Health Ethics Network. This conference, titled Ethics Dialogue in an Emerging Healthcare System, was attended by a variety of healthcare professionals and featured discussions on various ethical issues—euthanasia, assisted suicide, advance directives and others.

During these discussions, I often found myself pondering the implications of our increasing liberal attitudes in the above areas for people with disabilities. One discussion in particular, which centered around the issue of advance or medical directives—living wills—troubled me more than most.

At one point in the discussion, a sample of a medical directive was passed around for the scrutiny of the considerable numbers in attendance. Two passages in it immediately caught my eye:

"If at such time the situation should arise in which there is no reasonable expectation of my recovery from severe physical or mental disability, I direct that I be allowed to die and not be kept alive by medications, artificial means or 'heroic measures'."

"Measures of artificial life-support in the face of impending death that I specifically refuse are...mechanical respiration when I am no longer able to sustain my own breathing."

I acknowledge that people are becoming increasingly concerned with having control over the circumstances in which they die. But, as a quadriplegic who uses a respirator part time, I obviously have some grave concerns with the above passages.

There are the obvious questions about safeguards to prevent people, disabled or not, from being the victims of errors and poor judgment calls. My chief concern, however, is over the devaluing message that is implied about having a disability.

Over 40 years ago, when I had polio, it was obvious that there was "no reasonable expectation of my recovery from severe physical disability." Should I have been

given the opportunity, or my parents, to turn off my respirator—my "artificial life-support?" I can assure you that adjusting to my disability wasn't easy, but my subsequent years have been everything life is supposed to be—enriching, rewarding and, more than anything, precious.

Chances are that every one of us has heard people say that, if they were Christopher Reeves, they wouldn't want to continue living after the catastrophic accident which left him a quadriplegic dependent on a ventilator. Why, then, does Christopher seem so positive these days? In Canada alone, some 500 people a year become similarly disabled. How many take their own lives as a result?

"Coupled with fear and ignorance, these messages give false credence to many people's belief that people with disabilities are a burden."

I would suspect none. I'm not claiming that many don't initially consider it. I am claiming that, after a period of adjustment, most rediscover the joy of life; they realize there's more to it than walking.

Why, then, does the public express an outpouring of sympathy for Christopher Reeves after he no longer requires it? I believe that, in part, it's because of subtle messages such as those sent via the above passages. Such messages are pervasive in the medical community, which, in turn, holds considerable power in our society. Messages such as this give permission, however subtly, for others to believe that a person with a serious disability is worth less than an able-bodied person. Coupled with fear and ignorance, these messages give false credence to many people's belief that people with disabilities are a burden.

The well-meaning among us don't want to acknowledge it, but these beliefs do exist. Often, they translate into discrimination and, in the worst scenario, a lower standard of care in our medical facilities.

My greatest fear is that, as the concepts of euthanasia and assisted suicide become more accepted in the medical profession and society in general, and these subtle messages as written above become more pervasive and influencing, some unknowing person with a disability will pay the ultimate price. In hospital, unable to speak or communicate, this person will be the "beneficiary" of some well-meaning, sympathetic professional who will pull the plug. If this sounds like paranoia, please try and put yourself in the position of people who live with a disability.

This conference was a small-scale version of a much larger discussion of such issues that is taking place every day, all around us. In the midst of it, our federal and provincial governments continue to devolve

Status Report

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services and decision-making power to regional authorities. The danger in doing so is that crucial decision-making power is being handed over to people who may not possess wisdom or judgment necessary to ensure all people, regardless of ability, are treated with equality in life and death situations. Who knows what decision may be made by an isolated authority, particularly given our current emphasis on reducing out-of-control costs in our healthcare system?

My call to action, then, is to three separate groups. In responding to the public pressure for increased acceptance of euthanasia, assisted suicide and advance directives, the medical community must remain diligent to ensure the rights of people with disabilities are protected. Further, medical professionals must realize the full effects of language that devalues disability, and find ways to ensure that people with disabilities are viewed for their equal worth and status.

Governments, meanwhile, must find ways to ensure that regional authorities have a consistent approach that guarantees people with disabilities are treated with equality and fairness. In this province, I believe that

the provincial government needs to develop a code of clearly written values that all decision-makers and medical professionals must adhere to.

Finally, people with disabilities must take an even greater role to ensure their rights as citizens are not jeopardized. So, in closing, I salute the efforts of one man in particular: Mark Pickup of Beaumont, who has lived with MS for the past twelve years.

Recently, Mark was awarded the Kurelek Award by the Alliance For Life. The award is a recognition of the countless speeches and presentations Mark has made and letters he has written in support of life with dignity for people with disabilities. "At a time when cases like Latimer and Bastable suggest to society that it is better to be dead than disabled, Mark's work sends a message of hope; that disabled persons have gifts that society can ill afford to do without," said Alliance For Life president Chuck Smith in presenting the award.

If you're a person with a disability, Mark has been campaigning for your rights for a long time.

Perhaps it's time to join him. ♦

Thumbs Up...

...to the Red Deer Red Cross office, which is now offering first aid training to people with disabilities. First aid instructor Stacy Kleckner and safety services coordinator Shelley Hanlan are developing a program that will meet the needs of people who have a visual impairment or a physical or developmental disability. "In the end, they just want to have the confidence to respond to an emergency situation," says Kleckner.

Thumbs Up...

...to the North American Shriners for finally getting with the sensitive language program. At its national meeting in New Orleans, delegates unanimously voted to change the name of its hospitals from Shriners Hospitals for Crippled Children to simply Shriners Hospitals for Children.

Calgary Organizations Join Forces...continued

another part of the city to get technical information from TRC and to another part of the city to find out how to build their house. All of us have general information in most categories, but we all have specific information in the areas that we work in. Because of that, we can have a greater benefit to the client by having us all in the same location."

"It will provide streamlined access for clients," says Porteus, adding that clients of one organization will also easily become aware of the services of the other two once they're all under the same roof.

Finding and leasing that roof, however, may be a stumbling block preventing timely completion of the alliance. "We've been looking for about a year and a half," says Dianne Nickel, Executive Director of the Accessible Housing Society, which offers a variety of services aimed at allowing people with physical disabilities to live independently in community housing. "It's very difficult to find the size of space we need with sufficient parking. That's one of our biggest problems; accessibility is the other."

All three organizations, however, remain confident that suitable space will be found.

Even then, says Arndt, the headaches won't be over, as the organizations will have to deal with some growing pains. Arndt speaks from experience—three other CPA offices in Alberta currently share office space with other organizations. "There's going to be some glitches that we're going to have to work out, as organizations, in order to make it work." Arndt adds that such glitches will be in the form of territorialism and personality conflicts, but maintains that by remaining focused, outstanding issues will be resolved. "The goal is to be committed to the collaboration and to each maintain our own identity as well, so that we're perceived as a resource centre that helps the mobility impaired, but at the same time, as independent organizations with independent resources as well."

Nickel agrees. "This is a strategic alliance. It is not a partnership or merger. We each have our own identities. But there is a real commitment to work together."

In doing so, each organization firmly believes they can become better—something they feel they are obligated to strive for. "I think that we have a responsibility for good stewardship for the funding that's provided to us, whether it's through government or private fundraising," says Nickel. "Part of that is about collaboration."

Porteus agrees, particularly since TRC charges clients who are able to pay a fee for the service they receive. "Stewardship becomes a really big factor in that you're charging a client directly, so our concern is that they're receiving optimum service for the dollar they're spending. We're in the business of providing service in each one of our areas. If we think of ourselves as a business and approach it in a businesslike manner, I think we'll go further.

"We're in competition, or there are other individuals in competition with us, so it's a question of what can we provide in terms of an amalgamated, streamlined service that is going to make us, in the market, more attractive to the client." ♦



National Meeting Highlights

Fran Vargo, PhD.

Each year since the inception of the Premier's Council, we've met with representatives of similar bodies across Canada to discuss and plan coordinated action around areas of common concern. These areas usually deal with disability policy at the federal government level.

In June, our Council hosted this year's meeting. The backdrop for the meeting was ominous, with the federal government's recent actions around disability policy being perceived by Canada's disability community in a threatening light. These actions include restructuring federal payments to provinces for social programs without setting standards for how payments are spent, elimination of many programs developed under the National Strategy for the Integration of Persons with Disabilities which ended in March, the lessening of power of the Disabled Persons Secretariat within Human Resources Development Canada, and the elimination or reduction of funding to many

"The backdrop was ominous, with the federal government's recent actions around disability policy being perceived by Canada's disability community in a threatening light."

disability organizations. These actions, and others, appear to point to a trend within the federal government to give up responsibility for its leadership role in ensuring equality for Canadians with disabilities.

On the other hand, attendance at our meeting by federal government representatives, both elected and public service, was at an all time high. In total, four Members of Parliament and three federal government

employees were present (see list of attendees). Their presence indicated, at least, that the Chretien government is aware of the growing dissent among Canadians with disabilities.

With our colleagues from other provinces, we expressed to the MPs present our support for the Parliamentary Committee's 1995 report, *The Grand Design: Achieving the "Open House" Vision*. This report strongly recommended that the federal government assume national leadership for disability policy and that all disability policies and programs undergo a comprehensive review that would include significant community input.

Not surprisingly, we took the opportunity to strongly criticize the response to this report by Human Resource Development Canada (HRDC). It was felt that the response, entitled *A House Open to All: A Shared Responsibility*, lacked commitment to develop a national strategy on disability issues, and instead confirmed the federal government's intention to defer its responsibility as a leader in this arena to others.

We also criticized funding cutbacks to the Status of Disabled Persons Secretariat within HRDC. It was felt that these cutbacks could spell the end to valuable initiatives operated by the Secretariat, such as National Access Awareness Week. We unanimously approved a recommendation that urged the federal government to maintain a formal arms' length organization, such as the Secretariat, to address outstanding issues for Canadians with disabilities.

The meeting also provided us with an opportunity to discuss our common desire for national standards and provincial comparability, particularly in the area of the newly created Canada Health and Social Transfer (CHST). A recent federal report to the Premiers identified a series of guiding principles aimed at ensuring consistency on national social policy and the design and delivery of programs at the provincial level. While sympathetic to the good intentions of

1996 Annual Meeting of Councils: List of Attendees

Frank Jonassen, Director
BC Office for Disability Issues

Gary McPherson, Chair
Fran Vargo, Executive Director
Diane Earl, Director, Research and Policy
Wendy Buckley, Executive Assistant
Alberta Premier's Council on the Status of
Persons with Disabilities

Lydia Bardak, Executive Director
NWT Council for the Disabled

Wendy Dean, Director
Workplace Diversity, Saskatchewan Labour
Ernie Hasiuk, Director
Manitoba Vocational Rehabilitation Services

Reid Nicholson, Chair
Charles Macdonald, Executive Director
Nova Scotia Disabled Persons Commission

Sandra Latchford, Chair
Randy Dickinson, Executive Director
NB Premier's Council on Status of Disabled

Francie Harle, Assistant Deputy Minister
Alberta Federal & Intergovernmental Affairs
Sheila Finestone, MP, Chair
Ian McClelland, MP, Former Member
Parliamentary Standing Committee on
Human Rights and Status of Disabled
Persons

Andy Scott, MP, Chair
Anna Terrana, MP, Member
Task Force on Disability Issues, HRDC

Nancy Lawand, Director
CPP Program Direction, HRDC

Cathy Chapman, A/Executive Secretary
James Hicks, Program Officer

the report, we expressed concern about the difficulty of implementing the principles.

We all agreed that, alternatively, the federal government must maintain an active role in the development of social programs. We also agreed that it must develop adequate and enforceable standards for delivery of social programs, and that programs must be comparable from one province to another. CHST agreements, we emphasized, must be based on clearly written principles that guarantee the equality of persons with disabilities across Canada.

Finally, the current review of the Canada Pension Plan and its implications for peo-

ple with disabilities were discussed. Disability benefits delivered under CPP have been targeted for reduction. We expressed our concern that, if the CPP disability benefit is to be substantially changed, (or dropped all together, as some have proposed) it cannot be done without having a national income replacement program in place.

What will become of our criticism and recommendations? It's difficult to predict. But it was encouraging that the MPs present indicated their appreciation for the opportunity to attend the meeting and that they found the discussions enlightening. Also encouraging was a commitment to continue

to raise our concerns by the two MPs who are to be involved in the recently developed HRDC Task Force on Disability Issues—Anna Terrana and Andy Scott.

It would be prudent to remember, however, that the problems are serious and will not be easily resolved. I believe that continuous strong lobbying efforts with a consistent message by individuals with disabilities and their organizations will be the only way to bring about any measurable change. ♦

For a copy of a communiqué summarizing the meeting's proceedings, contact the offices of the Premier's Council.

Disability and Human Rights

Tough Words for Tough Times

Is the federal government absolving itself of its role as leader in setting disability-related policy? The Canadian Human Rights Commission clearly thinks so.

In introducing the subject in its most recent annual report (of which ten full pages are devoted to the discussion), the authors write, "There is a gloomy sense that, having made a gesture toward accommodation, the drive toward full social integration for people with disabilities has either stalled or run out of gas."

In the report, the Commission concedes that inaccessibility and marginalization are "giving way to the spirit of integration," but maintains that laws containing promises of equality remain largely unfulfilled. The choice for Canadian governments, continues the report, is to meet the objectives written into law or be prepared for "a period of painful and frustrating litigation."

Of prime concern to the Commission is the potential for people with disabilities to fall between the cracks after the demise of the five-year National Strategy for the Integration of Persons with Disabilities and during the continuing revision of social programs. In summarizing this issue, the authors write: "...disability issues require

coordination and collaboration within and among governments; the federal authorities should therefore develop a genuine strategy covering the whole gamut of disability issues..."

There are a number of other specific areas of concern outlined in the report. The federal government has failed to amend the Human Rights Act to clearly define employers' responsibility to accommodate persons with disabilities. Employment gains by people with serious disabilities are "achingly slow." Many federal bodies are still not committed to the principle of accessibility. Many federal bodies have a misunderstanding of the alternative communication needs of people with vision or hearing impairments. Finally, the Commission fears that a move toward transportation deregulation may erode advances and reduce the likelihood of remaining barriers being removed.

The Commission also gives praise to some federal bodies. These include the Department of Justice, which proposed changes aimed at ensuring the justice system is more satisfactory for people with disabilities; the Canada Pension Plan, which removed some disincentives for people with disabilities to leave the CPP program in favour of testing the employment waters; the Canada Stu-

dent Loans Program, which now provides further support to students with disabilities for necessary equipment and services; the CRTC, which is compelling all broadcasters to caption ninety percent of all broadcasts within eight years; and Canada Post, which is quickly renovating postal outlets for accessibility.

The bottom line, however, is that the current system of programs has largely failed to address the needs of Canadians with disabilities, and that the costs of these inadequacies are shared by all taxpayers in the form of unnecessary social allowance payments and the "lost contribution of people who need better access to training, transportation, or simply to the job-site."

"There is a crying need for leadership on this issue," write the authors, "and we feel obliged to say that the Federal Government has not carried its fair share of that load." ♦

—C.B.

*For copies of the Canadian Human Rights Commission's 1995 Annual Report, write or phone the Commission at its National Office: Canadian Human Rights Commission, Place de Ville, Tower A, 320 Queen Street, Ottawa, ON K1A 1E1
Tel. 613/995-1151 TTY 613/996-5211.*



Paratransit: USA vs. Canada

Diane Earl, Director of Research and Policy Review

Recently, I had the opportunity to attend a conference on mobility aids and public transit. Participants were from British Columbia, Alberta, Saskatchewan, Washington, California and Oregon. Discussions included marketing of accessible transit, customer information systems, travel training, paratransit (DATS, Handibus, door-to-door services) eligibility, mobility aid securement, bus technology and service audits.

For me, the most interesting aspect of this conference was the opportunity to compare differences in the approaches taken by the two countries involved, particularly in two areas of great interest to me—paratransit eligibility and mobility aid securement.

Naturally, the Americans with Disabilities Act (ADA) plays a role in the provision of accessible transportation. ADA is a civil rights law which we in Canada often speak of with envy. The ADA has determined, in law, that all citizens have the right to access public facilities and services. A reasonable expectation, indeed.

What does the ADA mean for the average person who has a disability and requires accessible transportation? It means that all transit buses must be accessible to the fullest extent possible. But the law also places a responsibility on the individual. If provisions have been made for wheelchair users to use public transit, they may no longer be eligible to use paratransit services. In other words, they don't have a choice about using paratransit or public transit. In municipalities where there isn't yet total accessibility, the operator of the paratransit services is only expected to transport these individuals on the inaccessible part of the trip to a transfer centre; there, they must use an accessible transit bus to complete their trip.

Eligibility for paratransit services is determined by the ADA. To be eligible, an individual must be unable to board, ride or disembark a transit bus; be unable to get to a transit stop; or live in a community which doesn't operate public transit. An individual

can be granted "conditional eligibility" which may mean, for example, he or she can use paratransit services during inclement weather.

In contrast, Canada has taken the voluntary compliance route with respect to the provision of accessible public transit services. Slowly, we are finding increasingly accessible transit services across the country. In Alberta, operators are moving towards accessible services and are replacing fleets with accessible buses as replacement

"...it's my sense that operators in Canada are realizing greater demand for their services because of the lack of full accessibility on conventional transit routes and broader eligibility policies and practices."

becomes necessary. Clearly, it will be some time before total accessibility is achieved. Meanwhile, people with disabilities in Alberta still have a choice of how they wish to travel, even if their destination lies on an accessible route. Eligibility for paratransit service in Alberta is determined by the operators, hopefully with input from users.

Although paratransit systems are experiencing growth on both sides of the border, it's my sense that operators in Canada are realizing greater demand for their services because of the lack of full accessibility on conventional transit routes and broader eligibility policies and practices.

In US municipalities, travel training is prevalent and used to teach people with disabilities how to use conventional transit. Again, once training is complete, and it's

determined that the person can safely use conventional transit, that individual is no longer eligible for paratransit services. In Canada, operators are considering travel training—but as a way to encourage people to use the accessible conventional system. I'm not aware of any plans to make policies that would insist that people with disabilities use accessible transit if it's available.

Are Americans with disabilities, with their ADA, better off than their Canadian counterparts? I can see the pros and cons of both approaches. For example, the ADA results in almost overnight accessibility. But critics of the ADA maintain there is a public backlash towards people with disabilities born out of resentment from having to comply with the law. In the US, I am told, some service providers are looking for loop holes so they don't have to provide accessible service and lawyers are getting rich as they argue for opposing sides.

Conversely, in Canada, it will take years to achieve the same level of accessibility. But perhaps there is a greater, lasting impact through voluntary compliance where people offer the service because they want to provide equality for all citizens and recognize the value of doing so.

With respect to paratransit eligibility, there are again pros and cons to each country's approach. Americans no longer have a choice. But, if integration is to be more than a buzz word, shouldn't those who are able have no choice but to use mainstream transportation? Canadians, of course, still have a choice. But, if a person lives on an accessible bus route and is able to safely use regular transportation, wouldn't it be hypocrisy to not do so? This Council, for one, has always maintained that people with disabilities don't want special treatment; they want equal treatment.

As for the securing of wheelchairs and scooters, the Canadian Standards Association (CSA) recently published two new standards: Z604-95 Transportable Mobility Aids and Z605 Mobility Aid Securement

and Occupant Restraint (MASOR) Systems for Motor Vehicles. The intent of the standards is to ensure the safe transportation of people using mobility aids while travelling on paratransit vehicles, but they have been criticized by some as being inflexible and paternalistic. Provinces will review the standards and each will determine if the standards will be adopted into regulation, either wholly or in part. A paratransit operator also has the option to incorporate the standards into its operating policy.

Alberta Transportation and Utilities (AT&U) has established a committee, made up of stakeholders, to review the CSA standards and provide advice on what, if anything, should be in regulation in Alberta. AT&U will share the findings of this committee with operators and users before making final decisions on just what Alberta standards need to be incorporated. Early



In the U.S., the ADA determines who rides paratransit and who rides regular buses.

indications are that AT&U will take a practical, relaxed view of these standards. Other provinces may be less flexible—Ontario,

for example, has a track record of being obsessively and overly concerned with “protecting” people with disabilities.

The US has yet to publish similar standards, but they are in the development stages with implementation some two to three years away. A comment from paratransit operators attending the conference indicated that, even if such standards are developed, there would be no requirement to enforce them. This would certainly be a much more relaxed way of approaching the issue. This, in turn, can be viewed in two lights. If you’re deeply concerned about safety at all costs, you may view a relaxed approach as reprehensible. However, if the standards are structured like the CSA’s, you may view them as overly protective and paternalistic, and the relaxed approach may appeal to you.

As usual, there is no black and white; there are only shades of grey. ♦

Barrier Free Recreation

Access for All at Fort Edmonton Park

A refurbished caboose now allows wheelchair users to tour Fort Edmonton Park in grand style.

The folks at Fort Edmonton have long laboured to make the park accessible. Ramps and wheelchair accessible washrooms help. But bumpy boardwalks and dirt roads aren’t great for wheeling around.

The logical way to tour the park, which offers a glimpse of Edmonton in its early years, is by boarding the steam train. The train is the park’s number one attraction, but it too has been largely inaccessible.

Enter the caboose, which was donated by Canadian National. A timely grant from Edmonton Parks and Recreation allowed the caboose to be spruced up and outfitted with a hydraulic wheelchair lift and wheelchair lockdowns for eight passengers.

Painted in the green and gold colours of the Edmonton Yukon and Pacific Railway, the park’s new caboose adds the finishing touch to the steam train and provides accessibility for all at the same time. ♦



Easy access at Fort Edmonton Park

—photo courtesy Fort Edmonton Historical Foundation

Getting the Gadgets You Need

Cliff Bridges

For years, here in Canada and around the world, people with disabilities have been attempting to impress upon others that they exist. "There are 4.2 million Canadians with disabilities," advocates have cried, pointing to the 1991 StatsCan results. Who's been listening? While governments can sometimes be accused of having ears stuffed with cotton, private enterprise cannot. The result has been an explosion of assistive technology aimed at people with disabilities.

In defining assistive technology, we're referring to any device that assists a person overcome the handicapping effects of a disability. Simple gadgets such as forks with big handles, complex computerized communication systems, and everything in between—for the purposes of this article, let's lump them together as assistive technology.

If we didn't take this simplified approach, the different categories of technology would occupy this entire article. There are devices for all types of disabilities. There are beach wheelchairs with balloon tires. There are fishing reels that cast and retrieve by electric motor. There are speech synthesizers that provide a voice for someone who can't speak. There are reading machines for blind people. There are environmental control systems. There are light bulb holders, shower chairs, driving aids. The list goes on and on, ad infinitum, and each product is available with a variety of options and in a range of sizes and designer colours.

More choice is good news. But choice inevitably means making difficult decisions. So what follows is our attempt to tell you how you might go about identifying solutions for your assistive technology needs and, ultimately, making a final decision.

How do you get what you need? It all depends on how thoroughly you want to approach the problem and to what extent you like to play a role in solving the problem. You can buy the first device that seems to provide a solution. You can research

and find the device that provides the best solution at the best price. You can also build it yourself—or have someone else build it—if you can't find a suitable, commercially available solution or if the price is too high.

Let's begin by assuming you'd like to find out what's available commercially. Obviously, you could rely on an occupational therapist for assistance, or you could make a stop at a home healthcare store. Keep in mind that, for some forms of assistive technology or to qualify for outside funding, a professional assessment is an absolute must. But, if not necessary, these "medical" oriented methods of gadget shopping may be limited and expensive.

One solution is to check out the catalogue mail order businesses offering assistive technology. There are several such businesses in Canada, including two that we told you about in the last issue of *Status Report*: Calgary-based Primetime (800/663-GIFT) and Toronto-based Friends (416/699-4446). These companies offer many general household gadgets aimed at easing daily living activities.

There are also companies and organizations offering catalogues containing more specialized equipment. For example, California-based Access to Recreation is a mail-order business specializing in exercise and recreation equipment for people with physical disabilities (see sidebar on page 10).

Looking for switches, environmental controls, and specialized computer access devices? Operated by the Canadian Council for the Disabled, TASH (800/463-5685) offers a catalogue chock full of this type of technology.

Another option, if you have the luxury of living in Edmonton or Calgary, is to contact or visit a technical resource centre. There are several excellent centres where you can see technology demonstrated or displayed and catalogues of other devices. In Edmonton, you can check out the Easter Seals Ability Council's Resource Centre (403/429-0137), or the Glenrose Hospital's Assistive Devices Service (403/471-2262). In Calgary, you can check out the Technical Resource Centre (403/262-9445).

There is an obvious advantage to accessing one of these centres—staff are trained experts and, particularly if you're looking at complicated gadgetry such as communication devices, often know exactly what you need. They may also be able to suggest avenues of financial assistance for purchasing products, and some may offer low-cost rentals—an ideal way to find out if a product is well-suited for your needs.

If there's any drawback with catalogue and resource centre shopping, it's this: you'll probably only get a look at one or two potential solutions. Let's say you're a quadriplegic looking for an environmental control system to give you further independence in your home. Not to suggest TASH's products aren't good, but what if they don't do exactly what you need them to? There are at least a dozen North American manufacturers of such systems. How do you find out who they are and which one offers the best product for you?

There are printed directories of assistive technology manu-



facturers available, and may allow you to go straight to all sources. An example is the Canadian Assistive Devices Directory, published by Medec in Ontario (416/620-1915). This directory is limited, however, in that it contains only Canadian listings (obviously, a wider range of products are produced south of the border). If you're an individual, it's also somewhat pricey at \$100.

Another method of identifying all providers of technology in a given area is to search your library for magazine reviews or books. For example, if you were interested in computer technology, a recently-published book, *Adapting PCs for Disabilities* by Joseph J. Lazzaro, would be an excellent

choice (see last issue of *Status Report* for a review). Magazines, including California-based *New Mobility*, also periodically review products; however, such magazines may not be carried by your library. (Note that the above-mentioned technical resource centres usually have well-stocked, disability-specific libraries containing books, magazines and catalogues.)

Increasingly so, your best source for research is the Internet, particularly if you live outside of a city. If you have access to a computer, modem and Internet account, you can accomplish more in a couple hours than you will in a week of conventional research using the above methods. Using a

web browser such as Netscape, you can visit websites such as the recently-established INDIE (<http://www.indie.ca>), touted as Canada's one-stop disability information website. INDIE contains a modest list of assistive technology providers and direct links to many more.

More rewarding yet would be to use a net search application such as YAHOO and, using keywords such as "assistive or adaptive technology", perform a search of the web. You'll be astonished at the results: hundreds of disability/technology websites across North America and around the world will be available at your fingertips. These

...continued on page 10

Free Advice From the Feds

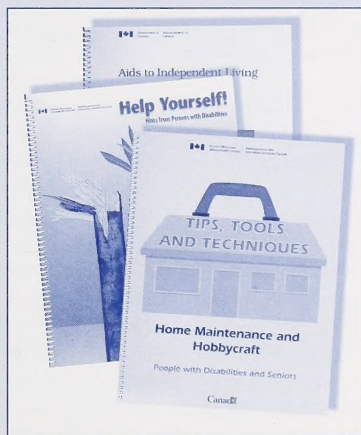
Three excellent manuals for the person with a disability seeking greater independence are available from Human Resource Development Canada.

Aids to Independent Living: Breaking Through the Barriers is a 125-page manual that describes hundreds of devices aimed at making everyday activities easier for the person with a disability. Many of the descriptions are of devices commercially available, but a considerable portion of the manual contains descriptions of how to build aids or adapt existing implements for a disabled user. For example, two methods of widening a knife handle for use by someone with weak grip are described: you could buy a length of Rubazote (a foam-rubber tubing) and slide it over the handle, or you could apply masking tape and then glue on a bicycle handle. Diagrams and drawings are provided throughout the manual, which has sections on kitchens, bathrooms, general household tips, personal care and recreation.

Help Yourself! Hints From Persons with Disabilities deals with similar material as *Aids to Independent Living*. But, while there is overlap, there's enough different suggestions in *Help Yourself!* to justify having both.

As the name suggests, this 129-page manual provides hints—many ingenious and slightly off the beaten track—from consumers. For instance, you'll find a suggestion on how to modify any bra so that it opens at the front by cutting the front and inserting a hook-and-eye strip. Another suggestion describes how to build a device that allows you to knit with one hand.

Once again, you'll find diagrams and drawings throughout. There are chapters dealing with personal care, kitchen storage, cooking techniques, housekeeping, reading and writing, safety,



recreation, vehicular and new technology.

The final offering is *Tips, Tools and Techniques: Home Maintenance and Hobbycraft*. If you're a handyman or hobbyist with a disability, you've probably found that tools and techniques for the able-bodied don't necessarily work for you. *Tips, Tools and Techniques* is a manual that recognizes your needs and recommends solutions.

The chapter on tools outlines all the basic tools you'd want to have in your toolbox. All tools included in the listings have features attractive to a person with a disability, such as light weight or large handles. Also included are tools, such as a holder for starting screws and nails, that are targeted specifically at

consumers with disabilities. Both hand tools and power tools are covered.

There's also numerous hints on how to adapt run-of-the-mill tools for use by the disabled handyman. For example, there's a description of how to mount a pair of visegrips on a prosthetic arm. Another section deals with widening tool handles with cylindrical foam padding.

The chapter on tips and techniques also has sections for hand tools and power tools. Examples of techniques for hand tools include starting a nail with one hand and extending a wrench for extra leverage. Techniques for power tool use include using a lap desk for drilling stock and support or roller stands when cutting stock on a table saw.

All three manuals were developed by working groups that included consumers with disabilities. They are produced in large print and are available in alternate formats. Best of all, they're all free: contact the Canadian Clearinghouse on Disability Issues at 800/665-9017. ♦

sites are often maintained by technical resource centres, universities, manufacturers and rehabilitation facilities.

An impressive site you're sure to run across is Trace (<http://trace.wisc.edu/>), which belongs to the Trace Center at the University of Wisconsin - Madison. A tour around this site will yield a great deal of information on assistive technology. Also available at the website is a compressed version of Abledata, a huge database of information containing information about some 17,000 examples of assistive technology. Abledata contains specific product information and detailed suggestions for choosing between products. Its only drawback is that it's a tiny bit unwieldy—it's a DOS application and won't run under Windows (there's also a Mac version). All in all, however, it's definitely worth downloading.

Keep in mind, as you cruise the Net, that sales hype is very much present in the assistive technology industry. This is especially true when you visit websites of product manufacturers. The main drawback of researching electronically is that, unlike a technical resource centre, you can't try out the product for yourself. A healthy degree of scepticism is probably needed; when you've identified some solutions, you may want to get more information, independent assessment or, ideally, a first-hand look at a product. And remember: many distributors of technical aids aren't as liberal-minded as your local Eaton's outlet when it comes to returning merchandise. If this is important to you, be sure to ask for a company's policy in writing.

The Internet, of course, is more than a storefront. It can provide the tools for holding forums and discussions about assistive technology. For example, close to home, the Alberta Consortium for Rehabilitative and Assistive Technologies (ACRAT), a group of interested professionals and consumers, has established a LISTSERV on the net. The goal is to allow people to freely communicate about assistive technology; consumers, for example, can have their questions answered by specialists. To subscribe to the LISTSERV, send an e-mail message to "majordomo@majordomo.srv.ualberta.ca" and don't put anything in the "regarding" or "subject" portion of your e-mail form. In the body of your message, include only "subscribe acrat". Send the message, and you should receive confirmation and instructions

Catalogue Shopping for Recreation Equipment

Seventeen years ago, Don Krebs became a C-6 quadriplegic as a result of a waterskiing accident. Recreation, however, remained a large part of Krebs' life.

In fact, Krebs is the founder of Access to Recreation Inc. of Thousand Oaks, California. Access to Recreation is a mail order business offering hundreds of recreational products for persons with disabilities. In the company's latest colour catalogue (that's Krebs and his dog, Eddie B. on the cover), you'll find some truly amazing products. Motorized fish-



ing reels, fishing aids, exercise machines, golf clubs for the wheelchair user, portable ramps, bowling pushers and grips, card playing accessories, and wheelchair gun mounts are some examples.

The catalogue also features books and videos on recreational pursuits for people with disabilities. Note that Krebs doesn't manufacture

any of the products featured in his catalogue; he's simply the distributor.

Krebs says he regularly ships to Canada. You can order a free copy of his latest Access to Recreation catalogue by calling toll-free 800/634-4351. ♦

on how to take part in the discussions. (Note: do not include quotation marks.)

What if, after all your research is completed, you can't find exactly what you need? Or, if you can find it, you find the price is a tad steep? Keep in mind that, before catalogues, before the Internet, before this explosion of technology, people used to make what they need, or have it made for them.

In recent years, chapters of the Tetra Development Society have sprung up in cities across North America, including Calgary (271-3950) and Edmonton (Guy Coulombe at 424-6312). The brainchild of Sam Sullivan, a Vancouver city councillor who happens to be a quadriplegic, Tetra matches people with disabilities with volunteer engineers who will tackle devices unavailable commercially or, if they are available, are very expensive. Take a glance through one of the society's annual reports and you'll quickly realize that Tetra engineers have come up with some awfully impressive gadgets at a remarkably modest cost.

Last, but certainly not least, don't underestimate your own abilities. In many cases, particularly where a gadget for daily living is required, there are many simple, inexpensive home-built solutions. And it's not as if you'll have to dream them up yourself—chances are, if you want it, someone has already done it, and the design and instruc-

tions are documented somewhere. For starters, Human Resource Development Canada has completed three manuals (see sidebar on page 9) dealing with practical solutions for everyday problems encountered by people with disabilities as they live and work in and around their homes. These manuals refer to commercially available products, but they also detail numerous solutions for making what you need. For example, for the one-handed person, a cutting board with a couple of strategically-placed nails will hold your food in place while you cut it.

There are many other similar manuals, some of which may be available at your local technical resource centre.

You may surprise yourself with your ingenuity and come up with a gadget that seems so useful that you can't believe no one's thought of it before. Well, maybe no one has! Your next gadget might be marketable. If you think you've struck gold, you'll be happy to know that Industry Canada recently launched an Assistive Devices Program Office (613/990-4316 or e-mail: laughton@clark.dgim.doc.ca), which is dedicated to expanding the burgeoning field. One of the mandates of this office is to put inventors in contact with manufacturers and marketers.

Who knows—your household gadget may become a household name! ♦

Four New Council Members Appointed

The Premier's Council is pleased to announce the appointment of four new members.

Michael Ross of Calgary is a museum consultant in the areas of heritage resource planning, documentation and communication. Most recently, he was contracted to the Alberta Museums Association to study access for people with disabilities.

Michael has considerable volunteer experience; currently, he is a board member of Transgenus International, an organization that assists tribal peoples with community development, and a member of the Muscular Dystrophy Associations of Canada and the United States. Michael has limb-girdle muscular dystrophy and uses a cane.

Dayla Maisey lives in Okotoks and works in market research for the Calgary Regional Health Authority. She has bachelor degrees in commerce and science from the University of Calgary. Several years ago, when her brother sustained a serious brain injury, Dayla became deeply involved in work in this area. Since 1992, she has worked in various capacities for the Southern Alberta Brain Injury Society. Dayla has considerable volunteer experience with other community organizations, including Alberta Children's Hospitals, United Way and the Canadian Cancer Society.

Anne Belohorec of Sherwood Park has been an active and vocal volunteer with the Multiple Sclerosis Society for many years. She has counselled other members of the society, made presentations to health care workers and students about living with a disability, and played an active role furthering accessible transportation in her community. Anne, who has had MS since 1982, is a gifted writer and has published articles on parenting issues and women's issues regarding disability and chronic illness. Currently, she is enrolled part-time in Athabasca University and is taking courses in psychology and sociology.

Toni Tallman lives in Calgary, but is a member of the Blood Tribe. The mother of

a child with a disability, Toni currently serves as a board member of the Aboriginal Disabilities Society of Alberta and president of the Calgary Native Disabled Society. She is a vocal advocate for the rights of Aboriginal children with disabilities and runs a parent support group at the Calgary Friendship Centre. Currently, she is in her second year of the Community Rehabilitation Program at Mount Royal College.

The new members will each serve two year terms and, with the eight other members, will meet on a regular basis to guide the Council's secretariat in its day-to-day work.

The four appointments fill vacancies created when Council members Everett Soop, Ray Hegerat and Kaye Brock finished their second terms. The Premier's Council would like to thank these outgoing members for their hard work and vision. ♦

Council's Research Director is a Heckuva Sport

Diane Earl, the Council's Director of Research and Policy, was recently inducted into the Canadian Wheelchair Basketball Hall of Fame.

For Diane, who was the first wheelchair user in Canada to achieve a degree in phys-

ed., receiving awards has become somewhat of a habit. Among the accolades she's been honoured with are a membership in the Alberta Sports Hall of Fame and the Governor General's Award.

Congratulations, Diane. ♦

New Barrier Free Consulting Service

A recently formed St. Albert consulting company specializes in identifying accessibility flaws during the design and presentation phase of architectural development.

Designs by Caldwell is owned and operated by David Wulf, who has a unique combination of experience: for 27 years, he's been a wheelchair user, and he has 21 years experience as an architectural technologist. Wulf has designed commercial, multi-family and residential buildings, and has also written educational texts on residential home construction.

Wulf says that he's aware of an increasing number of architects and designers with an acute need for assistance when dealing with barrier free concepts for institutional, commercial and residential structures.

"Many buildings that may be considered accessible by the non-disabled in reality have steep and poorly located ramps, parking stalls too narrow or poorly located for access during inclement weather, and interior design barriers such as improper door swings, doors too heavy to open, and washrooms with inaccessible stalls," says Wulf. "These flaws need to be addressed during the presentation and design process to eliminate the future expense involved in correcting them."

Wulf offers his consulting services in three main areas: public and private commercial, government and institutional buildings; motel, hotel and other tourist facilities; and public and private air, train and bus transportation systems.

For more information, contact Designs by Caldwell at 403/459-3664. ♦

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3 3286 51076 8803**Seminars, symposia, conferences, meetings**

Calendar of Coming Events

The Injury Prevention Centre presents the sixth Injury in Alberta Conference. October 8 to 10, 1996, in Kananaskis. Theme: breakthroughs in injury prevention. Contact: the Injury Prevention Centre at 403/492-6019.

The Alberta Therapeutic Recreation Association presents the 11th Annual Symposium. October 25 and 26, 1996, in Edmonton. Theme: leisure links—partnerships for change. Contact: Jill Kelland at 403/472-5558 or Janice Rachinski at 403/428-1776.

The Alberta Congress Board presents Values and Ethics for the 21st Century. October 31 to November 3, 1996, in Banff. Theme: values and ethics as underlying forces for change and development. Contact: Alberta Congress Board at 403/421-9330.

The Community Care and Public Health division of the Capital Health Authority presents Designing Community Health. November 24 to 26, 1996, at the Fantasyland Hotel in Edmonton. Theme: breaking the barriers and shifting resources to deliver a community-based health system. Contact: 403/492-6868. ♦

Is your association or agency sponsoring a provincial or national conference or workshop? If so, please forward the pertinent information to:

The Premier's Council on the Status of Persons with Disabilities

250, 11044 - 82 Avenue

Edmonton, Alberta T6G 0T2

Tel: 422-1095 (Edmonton)

or 1-800-272-8841 (rest of Alberta)

Fax: 422-9691

Free Fitness Guide From CPA

If you're a person with a spinal cord injury looking for some sound advice on fitness, you'll want to contact your local Canadian Paraplegic Association office for a complimentary copy of *On the Road to Health and Fitness: A Starter's Guide for People with Paraplegia*.

This twelve page mini manual covers a lot of ground: benefits of exercise, descriptions of sports and exercise for the wheelchair user, and how to determine workout intensity and frequency, which will differ from individual to individual, depending on level of injury. There's also sections on aerobic and strength training programs, injury prevention, nutrition and weight control.

People with spinal cord injuries must consider some unique factors when starting an exercise program. For example, temperature regulation is very important, since the body's

On the Road ... to Health & Fitness



A starter's guide for people with paraplegia.



mechanisms for controlling overheating—sweating and diverting blood to the skin—are less effective after injury. Another example is the importance of a balanced strength training program to compliment any aerobic fitness program. Aerobic training alone may result in muscle imbalances, making a person susceptible to injury when performing transfers and other daily activities. *On the Road to Health and Fitness* addresses these areas of concern unique to people with SCI.

On the Road to Health and Fitness was written by a team of six writers who collectively have a great deal of expertise in rehabilitation medicine, physical education and sports nutrition. The project was sponsored by the Canadian Paraplegic Association's National Office and funded by the Rick Hansen Man in Motion Legacy Fund. ♦

